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Suggested running head: Existential experiences after curative cancer treatment

An exploration of the existential experiences of patients following curative treatment for cancer: Reflections from a UK sample.

Anna S. K. Lagerdahl<sup>1</sup>, Manus Moynihan<sup>2</sup> and Brian Stollery<sup>2</sup>

<sup>1</sup>Cancer Services, Great Western Hospital, Swindon, UK

<sup>2</sup>School of Experimental Psychology, University of Bristol, Bristol, UK

Author Note:

Correspondence concerning this article should be addressed to:

Anna Lagerdahl, Palliative Care Office, Dove Unit (3<sup>rd</sup> floor), Great Western Hospital,  
Swindon, SN3 6BB, UK

Telephone number: +44 (0)1793 605323

E-mail: [anna.lagerdahl@gwh.nhs.uk](mailto:anna.lagerdahl@gwh.nhs.uk)

# Abstract

The existential experiences associated with cancer diagnosis and treatment is well researched, but the post-treatment phase is relatively under-explored. Using semi-structured interviews and theory led thematic analysis this qualitative study investigated the existential experiences of eight cancer survivors who had successfully completed curative treatment. Being in remission had led to deep existential reflections (i.e. death anxiety, freedom, isolation, and meaning making) and some participants faced considerable challenges that impacted on their emotional well-being. Understanding cancer survivors' existential challenges should enable healthcare professionals to engage with the emerging shift from the predominantly medically focused post-treatment care to a more holistic approach.

**Keywords:** cancer, existential, curative, post-treatment, meaning, psychosocial oncology care

## Introduction

Research into the experiences of individuals with cancer suggests that the disease may give rise to a range of existential concerns, including fear of death, loss of meaning, uncertainty, vulnerability and isolation (Henoch & Danielson, 2009). If resolved, existential concerns can lead to a sense of redefinition, improved quality of life and positive health outcomes (Bowie, Sydnor, Granot & Pargament, 2004). However, when left unresolved, they may impact negatively on patients' well-being (Hinnen, Hagedoorn, Ranchor & Sanderman, 2008) .

Although research into the existential experiences of individuals with cancer is extensive and has provided useful insight into patients' needs during *diagnosis* and *treatment*, relatively few studies have focused on the *post-treatment* period. This parallels cancer care in the UK in general, which has traditionally tended to focus on patients' needs in the diagnostic and treatment phase. Post-treatment care has instead largely taken a medical approach in the form of surveillance tests and investigations for recurrence (Department of Health, Macmillan Cancer Support & NHS Improvement, 2010).

In recent years, a considerable increase in the number of cancer survivors (Maddams et al., 2008) has led to a more holistic focus being placed on the post-treatment phase and several studies have examined the needs of individuals following the end of treatment. These have highlighted that cancer patients experience unmet needs in the psychosocial, physical, sexual and occupational domains (Armes et al., 2009; Cancer52, 2009). In addition to these areas, early research studies have also indicated that survivors may experience unmet needs in the form of existential concerns (Hodgkinson et al., 2007; McKenzie & Crouch, 2004).

## Existential concerns

The term 'existential' is commonly used both in research and the wider literature. It is a broad term, which stems from the work of several authors, including Heidegger (1962), Kierkegaard (1957), Sartre (1956, 1963), Frankl (1969, 1972), and May (1950), to name a

few. Although attempts have been made to define existentialism, there is a general consensus that such a definition is difficult and many philosophical texts therefore describe existentialism as relating to themes of existence; such as being, choice, freedom, death, isolation, absurdity and meaning (Yalom, 1980). In his writings on Existential Psychotherapy, Yalom draws on the work of several existential authors and outlines four key existential concerns, namely 'death', 'freedom', 'isolation' and 'meaninglessness', which he considers essential to the human condition.

*Death:* Yalom (1980) suggests that "*the awareness of the inevitability of death and the wish to go on*" is a core existential conflict and a fundamental source of human anxiety. Although arguably present in all human beings (Meissner, 1958) death anxiety is often exacerbated when the nature of one's existence is brought sharply into focus. However, awareness of one's death can also have positive influences on the individual. Heidegger (1962) suggested that it can serve as a catalyst of shift into a higher mode of existence, with Yalom adding to this by suggesting that acknowledgment of one's mortality can add a sense of poignancy to life and lead to a more authentic way of living.

*Freedom:* From an existential point of view, 'freedom' refers to the uncertainty and lack of existential structure in life and emphasises the fact that all individuals are authors of their own lives. Although the world may seem structured, all individuals are ultimately responsible for their own lives (Heidegger, 1962), the choices they make and their actions (Sartre, 1956). Sartre (1956) also emphasised that awareness of freedom concerns, not only the responsibility to act, but also the failure to do so. Yalom (1980) argued that existential freedom and the uncertainty that accompanies this can give rise to a sense of 'groundlessness' and anxiety so overwhelming that many 'defend' against it by seeking relief in the form of external structure, predefined frameworks and authority.

*Isolation:* Existential isolation is often seen as stemming from experiences relating to death and existential freedom. Yalom (1980) defines dying, or awareness of one's own death, as

one of the loneliest human experiences. He goes on to emphasise that all human beings enter and leave life alone. No matter how close we become to one another, we are still responsible for our own life script and there will thus always be a degree of separation between oneself and the rest of the world. Heidegger (1962) advocated that there will come moments for all human beings when their sense of familiarity with the world, and belonging within it, is suddenly stripped away. Fromm (1956) identified existential isolation as the most primal source of anxiety for the human being and claimed that most individuals try to eliminate their isolation by developing strong associations with other human beings, groups or divine entities.

*Meaninglessness:* In his extensive work on the importance on meaning, Frankl (1972) described existential neurosis as being synonymous with a crisis of meaninglessness and estimated that about 20% of the neuroses experienced by his patients had been brought on by a sense of lacking meaning in life. The importance of meaning was also emphasised by Jung (1966) and Maddi (1967), who equated meaning with 'fullness of life'. Links such as these propose a need for all human beings to establish a sense of meaning in their lives. However, within the concept of meaning lies a great paradox: In the search for meaning, the individual is inevitably also faced with the concept of existential freedom, which posits that all human beings have to make their own choices and that there exists no absolute 'true' meaning. As a result, the individual has to create their own meaning, which may in itself give rise to emotional distress and a sense of hopelessness (Yalom, 1980). Yalom (1980) and Erikson (1963) both argued that prior to the development of a satisfying sense of meaning, the individual must first establish a coherent sense of self-worth and identity. Yalom goes on to suggest that the key sources of meaning are usually found in 'Creativity', 'Hedonism', 'Self-actualisation', 'Altruism' and 'Dedication to a cause'. Research suggests that meaning can be found in all experiences of life, including sickness, suffering and pain (Landmark, Strandmark & Wahl, 2001; Ramfelt, Severinsson & Lützén, 2002).

Yalom's (1980) work is by no means the only way of conceptualising existential concerns but it is a well-documented framework that has been adopted by clinicians and researchers alike. Furthermore, Yalom's work also differs from that of many other existential authors in that he places particular emphasis on the clinical manifestations of existential concerns, and how to work therapeutically with these. In the cancer literature, the term 'existential' is sometimes used interchangeably with the term 'spiritual', although the latter sometimes also refers to religion (e.g., Mickley, Soeken & Belcher, 1992). For the purposes of this paper, the term 'existential' will be used to describe themes of existence, such as being, choice, freedom, death, isolation, absurdity and meaning.

#### Existential concerns following end of treatment

As indicated above, despite the extensive body of literature examining the existential concerns of individuals with cancer, very few of these studies have looked specifically at the post-treatment phase. Some researchers have, however, examined existential experiences as part of *wider* research objectives. For example, explorations of the discordant feelings of cancer survivors have shown that many individuals who had been symptom free of cancer for up to two years tend to experience existential concerns relating to isolation and death (Crouch & McKenzie, 2000). Similarly, an examination of the supportive care needs of women following treatment for a gynaecological cancer by Hodgkinson et al. (2007) found that the participants had experienced changes in beliefs, questions about the meaning of life and increased anxiety around mortality.

Other studies have focused on *specific* existential experiences following the end of treatment. Rosedale (2009) found that women who had completed treatment for breast cancer experienced a considerable sense of isolation. This was depicted in the form of 'survivor loneliness', which encompassed a sense of being alone in the awareness of one's mortality and an altered sense of identity. Park, Edmondson, Fenster & Blank (2008) examined the meaning making efforts of individuals with a variety of cancer diagnoses and

found that these were significantly linked to the adjustment process following end of treatment.

Although the above studies are useful in increasing understanding around some of the existential concerns experienced post-treatment, their findings are limited to their specific areas of focus and hence only give a partial understanding of the field. A small number of studies have attempted to explore patients' existential experiences following treatment more fully. In a qualitative study involving an Icelandic population, Halldorsdottir & Hamrin (1996) explored the existential challenges of individuals who had completed treatment for a range of cancers. Participants were asked to reflect on their 'personal experience of having cancer' and their responses were grouped into the five subthemes of 'uncertainty', 'vulnerability', 'isolation', 'discomfort' and 'redefinition', all of which the authors deemed expressed the experience of existential challenges. The findings of the study also supported ideas previously proposed in the literature (e.g., Yalom, 1980), that existential experiences can lead to redefinition of roles and goals but also provoke intense feelings of anxiety. In a similar qualitative study, Westman, Bergenmar & Andersson (2006) interviewed Swedish breast and prostate cancer survivors, who had completed treatment with curative intent. As with Halldorsdottir and Hamrin's study, the participants were asked to reflect on 'their experience of cancer'. Findings tended to fall within one of three themes, namely 'life', 'illness' and 'death'. The study also showed significant links between the disruptions the participants felt the cancer had had on their lives, especially physically, and their ability to find meaning within the experience.

Another important finding in the Westman et al. (2006) study was that all the participants in the study had wanted to discuss their concerns with their health providers but the majority had not known how to, nor had they felt encouraged to do so by the health professionals. This was identified as an important indication that nurses need to increase their knowledge and awareness of existential concerns in order to be able to discuss these with patients. These suggestions were echoed by Pascal & Endacott (2010), who used Heideggerian



theory to explore the existential experiences of Australian cancer survivors with varying diagnoses. The core existential themes found related to 'uncertainty around recurrence and metastatic disease', as well as 'the experience of cancer as a transitional/turning point'. These existential themes were strongly linked to the emergence of emotional distress. Pascal & Endacott concluded that there is a considerable need for cancer services to become more skilled in addressing existential challenges with patients after the completion of their treatment.

The findings of the above studies all bring important understanding to the experiences of patients following the end of their treatment and provide a useful foundation on which to base further research. It should, however, be noted that the studies are still relatively low in numbers and their methodologies and designs have certain limitations. Firstly, the majority have looked at specific cancer diagnoses, rather than the shared experiences of patients following end of treatment. Of those that have examined the shared experience, there are other limitations. For example, in the Halldorsdottir & Hamrin (1996) and Pascal & Endacott (2010) studies, the participants differed in their prognoses, with some being at the terminal stages of cancer. It is possible that the existential challenges faced by individuals approaching end of life may in fact vary substantially from those in remission, and would therefore be better examined separately. Furthermore, Halldorsdottir & Hamrin (1996) and Westman et al. (2006) both asked the participants to reflect on their personal experience of *having cancer*, rather than the post-treatment period itself. Because of this, it is difficult to determine whether the findings of these studies are exclusively applicable to the post-treatment phase or whether they may also include experiences stemming from diagnosis and treatment.

To summarise, the present research base has indicated that existential concerns are often present following the end of cancer treatment. However, it is unclear whether existing findings apply exclusively to the end of treatment with curative intent, and whether they are applicable to the *shared* experiences of individuals with different types of cancer. With this in

mind, the current study aims to explore the existential experiences of patients who have undergone treatment with curative intent for a range of cancers, and are considered to be in complete remission. As no previous research has been conducted in this area with the suggested participant group, the study will use an exploratory qualitative design.

## **Methods**

### **Participants**

Eight participants took part in the study (five female and three male). The participants were recruited using purposeful sampling and included individuals who had attended cancer services at a hospital in the south-west of the UK in the past year. Participants had to be of working age, have completed first-line treatment within the previous 12 months and be in complete remission. In addition, eligibility criteria also stipulated that the participants should not have been diagnosed with any other life-threatening illness within the previous five years.

The participants who took part in the study were all Caucasian UK residents with an age range of 43-62 years (mean = 55 years). The participants' cancer diagnoses included prostate, breast, skin, lung, and head & neck. The participants had undergone a range of treatments, including surgery (n=4), robotic (n=1), and mixed (surgery and chemotherapy n=1, surgery and radiotherapy n=1, or all three n=1). At the time of interview, the mean time since treatment ended was 8 months (range = 2-12 months).

### **Procedure**

Full ethical approval was sought and gained from the NHS Regional Ethics Committee (Ref: 10/H0203/42) and on this basis site specific ethical approval was secured from each local NHS Trust. Potential participants were initially contacted via telephone to gauge interest. Following positive response, an information sheet and a consent form were sent out in the post. This was followed up one week later via telephone to reassess interest in participation

and answer any questions. The eight participants who consented to participation were interviewed in a private room at their local hospital.

Prior to the interview, issues about confidentiality and anonymity were discussed with participants and they were also given the opportunity to ask further questions. Due to the range of definitions of existential experiences, the participants were given a brief definition and shown a list of potential existential concerns, as identified in the recent literature (Hench & Danielson, 2009). It was explained that this list was not exhaustive and merely intended to encourage discussion about their experiences. The participants returned the sheet when they had read it, in order to minimise bias and allow themes to emerge naturally from the interview. The interviewer employed open-ended questions, designed to allow the participants to explore their experiences since completing treatment. Follow-up questions and prompts were used to explore issues raised in more detail. The interviews lasted between 60 and 90 minutes.

### Analysis

Interviews were recorded digitally and transcribed verbatim. Theory-led thematic analysis was used to analyse these data. Thematic analysis makes a realist assumption about the nature of communication and focuses on the extraction of the dominant themes in the research participants' stories (Braun & Clarke, 2006). In theory led thematic analysis, the interviews are analysed to allow for the extraction of pre-established themes, as outlined by a specific theory (Hayes, 2000). This approach was employed as it allowed for the analysis to focus on key constructs within the existential literature (Yalom, 1980), as intended by the research aims. Credibility checks were provided using inter-rater reliability and triangulation (Yardley, 2000). Furthermore, all the themes discussed are grounded in examples from the participants (Elliott, Fischer & Rennie, 1999).

### Results

The thematic analysis identified four major themes: 'Death anxiety', 'Freedom', 'Isolation', and 'Meaning making'. Each of these themes contained several subthemes, which will be discussed.

### **Theme 1: Death anxiety**

The super-ordinate theme 'death anxiety' was omnipresent in these data. Death anxiety was expressed through the subthemes 'mortality', 'control' and 'more authentic way of life'.

#### **Subtheme 1 – Mortality**

Participants spoke about how the cancer had triggered thoughts about end of life issues, ageing, and dying. Many reported a heightened sense of mortality despite having completed seemingly successful treatment regimes.

*...so, this sort of like little procedure, this thing that I have gone through has sort of highlighted things that ... you know, we are going to die somewhere along the line. (#6 p.9)*

*It does make you think about your own mortality a little bit. You don't know what's, what's going to come up and what illness is going to happen to you. (#2, p. 6)*

#### **Subtheme 2 – Control**

A number of participants directly reported a need for control or an awareness of the lack of control they had experienced since completing treatment.

*...to deal with being ill and then not being in control because ... if you die I like to think of being in control, you can't be in control of that but I feel I need to be. (#5 p.10)*

*... if it's something you have absolutely no control over it's a little more scary I think. (#2 p.19)*

*I am more afraid of being ill, or not being in control... yes more apprehensive, I suppose, of having been ill and knowing what it's like. (#8 p.6)*

### Subtheme 3 – More authentic way of life

Participants described how they had reassessed many aspects of their lives since completing treatment. This had resulted in a new appreciation for life.

*...the realisation of what can happen...we are only here once... try and make the most of what you've got and try and make the best of your time. (#6, p.22)*

*I just appreciate things a little bit more...It sort of, I don't know, gives you a kick up the backside and makes you realise...that life is pretty good actually. (#7, p.14)*

Many participants also described a change in their attitude towards work.

*...you don't do anything else and it just becomes work, work, work and I just thought, "I don't want that anymore, there is more to life than work, work, work". (#3, p.10)*

*I'm going to retire as soon as I can... It is better to do that when you have still got time, still got health. (#6, p.13)*

Others had noticed a difference in the way they related to others.

*... you try not to have lots of petty arguments (#5 p. 19)*

*I do feel as if I am softer. I do feel I am more empathic, I do feel as if I understand other people who have been ill better than I did before, more sympathetic about that, and more sympathetic about people not being able to do things. (#8, p.17)*

## Theme 2: Freedom

The super-ordinate theme 'freedom' was also expressed in every interview. Participants spoke about several areas relating to existential freedom, namely 'uncertainty', 'seeking structure', 'awareness of authorship' and 'will to act'.

### Subtheme 1 – Uncertainty:

All participants gave emphasis to the uncertainty that followed end of treatment. Often this related to uncertainty around recurrence but in many cases it also related to a lack of structure, which seemed to be at stark contrast with the structure that existed during treatment.

*...there is a lot of information available before the treatment and during the treatment but not a lot of helpful information about after the treatment. (#1, p. 19)*

*...nobody seemed to be able to say to me "well, you know, you definitely need to be very cautious and it's likely to come back". (#2, p.2)*

*To be honest, I don't really perfectly understand what the, the medical situation is going forward. (#7 p. 19)*

### Subtheme 2 – Seeking structure:

Several of the participants also described the ways in which they had reacted to the lack of structure or sought to remedy this.

*I was like 'oh, now where do we go from here?' (#2, p.15)*

*Being at home just wasn't normal, so I just wanted it all back to normal, so I think that was why I was frustrated. (#7, p.4)*

*I was reading up about it more [after ending treatment]. Even though I knew about it before, I needed to go back to it and learn more about it. (#5, p.24)*

### Subtheme 3 – Awareness of authorship

Many participants additionally described how the experience of cancer had helped them gain a new level of awareness around their ability to make different choices.

*You know, it makes you think, you know, "ok well what do I want out of life, do I want to carry on working full-time, do I want to work less and have more time for other things?"... (#3 p.18)*

This newfound sense of authorship and responsibility was present even when they chose not to act, or made decisions which may have had an adverse effect on their lives.

*At work I have a reasonably senior position and can influence change in the business, yet I don't want to. (#7, p.7)*

*So you know, it's up to me to come to terms with that, or to change it. I have opted not to do some of the things that would change it because I don't want to do them...and that means...that's my fault. (#8, p.16)*

#### Subtheme 4 – Will to act:

For some participants, with the awareness of authorship and responsibility came a will to change things, such as taking positive action towards improving health.

*About 6 months after treatment I took a decision about trying to have a healthier lifestyle and yeah, perhaps taking a bit more responsibility for things like diet and exercise. (#2, p.5)*

*Rather than saying "there is great wealth of uncertainty spread out before me and I don't know what I am going to do", well in my case I knew exactly what I was going to do... (#1, p.17)*

### Theme 3: Isolation

Participants expressed a range of ways in which their illness carried nuances of existential isolation. These include 'emotional isolation', 'marked by illness' and 'protective relationships'.

### Subtheme 1 – Emotional isolation

All participants made reference to ways in which the experience of cancer had made them feel different from other people.

*There is a sense of isolation that the illness isolates you. You feel isolated inside this illness. That people can't reach you and you can't reach them. Because you have got this illness around you like a hard crust really, that no one can get in or out of. (#8, p.18)*

*It's the c-word, isn't it? I said "we are going to have a chat about my cancer", and there was a little silence. (#6, p.10)*

*I'll tell my friends about it and that's it... I won't keep talking about it sort of thing. We'd have to keep the conversation safe. (#5 p.7)*

This sense of difference persisted even when participants were in contact with other individuals with cancer, or with cancer services.

*Unfortunately they didn't have all the symptoms that I had, that was the problem, wasn't it? (#4, p. 23)*

*Everybody is different and a lot of what you go through is a little bit emotional and a little bit tied to you as an individual and it is not particularly physical as such, and it is a little bit vaguer. (#1, p.2)*

*This is massive to me and to everyone else involved it's not, to everyone else it's what they do all day long (when talking about contact with healthcare professionals). (#7, p. 28)*

### Subtheme 2 – Marked by illness

Participants also commented on ways in which the experience of cancer had changed them physically and made them feel different, sometimes for the longer term.

*They said: "You can't be a blood donor because we're not too sure if you have these cells going around or anything". (#2, p. 16)*



*My memory is affected and I don't know if that is the drugs or whatever. (#3, p. 16)*

### Subtheme 3 – Protective relationships

On the other hand, many of the participants talked about how the experience of cancer has led to an increased sense of closeness with family and friends. For some, there was an awareness of how this added closeness was linked to the sense of insecurity brought on by their illness.

*We have always been pretty close and we have always been able to talk about things...maybe it has brought us a bit closer. I suppose... anything to do with health issues you can feel a bit more insecure I guess. (#2, p. 19)*

Others talked about it more generally.

*We have a bit of a Friday club going now; if I finish early we'll go to the local hostelry. (#6, p.6)*

*I think my relationship with my wife is stronger...I appreciate her a lot more than I did. (#7, p13)*

And some also emphasised the support they had received from their religious community:

*The Church supported me and I'm a Christian and I know that people prayed for me (#3, p. 12)*

The impact of going through the experience of cancer alone was particularly recognised by some participants.

*If you are a single person, that must be a nightmare, to leave and go through what I've gone through, and be living on your own...I think I have managed because of strong family support. (#7, p.28)*

*I also live by myself, and I have been on my own for a very long time, and I have very, very little family...and I think that has made the whole process of dealing with being ill much more difficult. (#8, p3)*

#### **Theme 4: Meaning**

Meaning formed a considerable part of participants' accounts around completing treatment. Whereas some participants reflected on experiences relating to 'loss of meaning', many frequently also talked about ways in which they had gained a new sense of meaning ('meaning making').

##### **Subtheme 1 – Loss of meaning**

The loss of meaning that the participants had experienced was evident on several levels.

*Pointlessness:* The uncertainty of the future was very difficult for some participants, leading to an overall sense of pointlessness and lack of purpose.

*And there is a lack of a sense of purpose, because if you may only have a year or two left, I don't know what's the point of only having a year or two, there just doesn't seem to be any point. Might as well go now. (#8 p.18)*

*Loss of identity:* Some participants also reflected on ways in which they had experienced a loss of certain aspects of self and how this had led to a difficulty in knowing how to make sense of life. In some cases, this related to perceived gender roles:

*It's a challenge that I feel myself and I suppose in some respect it's a part of the male psyche... but, not being able to do what men do is quite difficult to cope with. (#1 p.12)*

*When you're the male of the household... there's things you normally do. The fence started to blow down and my wife went out to stop it blowing down, and I went out to help her but I just couldn't do it, I was so weak. (#7 p.5)*

At other times the loss related to more general characteristics:

*I feel less strong and less independent. I think before I was very strong and very independent, very confident...and yes, that has made me more apprehensive about the future I think. (#8, p.6)*

## Subtheme 2 – Meaning making

Participants described various ways in which they had engaged in meaningful activities since ending treatment.

*Hedonism:* For many participants, enjoyment and engaging in pleasurable activities had become a considerable priority.

*Really, it's about taking full advantage of what's happening now. Enjoy life to the full as much as you can. (#4 p.12).*

*So, if you want the kitchen revamped, there's me in the past "oh we can't afford this, let's wait". But no do it, let's get it done. Not that we try to go into debt but if there is x amount of money yes ... and that's probably been a positive thing I think. (#6 p.18).*

*I guess I feel what's more important, you know, it's just about enjoying life and enjoying my family and doing things that we enjoy and getting pleasure from everything and not worrying about it anymore. (#7 p.19).*

*Dedication to a cause:* Most of the participants reported that particular areas of their lives had been given a new focus since the completion of their treatment.

*... it allows me to do more things with the children after school, you know get them involved in activities. And you know, holidays, we can actually go out and do things. (#2 p.8)*

*I have taken up archery with my son. And it sounds a bit corny but it's one of those things for years I have always said "I want to have a go at that". And then my son said "yeah I want to have a go at that". And I'm of this mind "well let's do it then, stop talking about it and go and do it". (#7 p.8)*

*Altruism:* Many participants also reported a sense of fulfilment by engaging in activities that could benefit others.

*I feel now, I could, I could help other people, somehow volunteering. You know I have said to my wife 'cause I want to try and give some people my story because look, it can be alright.*  
(#7 p.28)

*I belong to a church and to be able to just be available for other people at some time and just to have that space... and if someone needed something I could just go and help them* (#3 p.10)

## **Discussion**

The aim of this study was to explore the shared existential experiences of individuals who had completed cancer treatment with curative intent. The study also hoped to identify patients' potential care needs around these concerns. Findings both support and add to those of previous research studies. They suggest that the experience of being in remission after the completion of treatment with curative intent may lead the individual to engage in a deep reflective process around the very core aspects of their existence. Although this experience carries many common themes with that of individuals at other stages of the cancer journey, it also contains some novel experiences.

### **Death anxiety**

The results of the study suggest that awareness of mortality and increased reflection around death are shared experiences for individuals who have completed treatment with curative intent. Despite being in remission, participants had become more aware of the finiteness of their lives and many expressed fear and anxiety around having very little control over this. These findings support those of previous studies, which indicate that a diagnosis of cancer frequently gives rise to increased awareness around life and death, and causes people to confront their mortality (Day, 1986; Landmark et al., 2001; Westman et al., 2006). This

awareness has in turn been shown to give rise to feelings of both anxiety (Hodgkinson et al., 2007) and depression (Yalom, 1980) and can cause patients to feel that they have very little control over their lives (Xuereb & Dunlop, 2003). Although it has long been known that increased awareness around mortality is a common experience for many individuals diagnosed with cancer, the results of the present study confirm that such feelings can continue to play an active role in patients' lives several months after they have completed apparently successful treatment regimes.

Having said this, increased awareness around mortality had frequently also led to positive consequences for the participants. Many reported that the completion of treatment had been followed by reassessment and newfound appreciation for life. Heidegger (1962) and Yalom (1980) have both emphasised how confrontation with one's mortality can be a trigger to a more authentic way of life and higher mode of existence. Since the completion of their treatment, participants felt that they appreciated life more and therefore wished to make the most of it. For many, this had involved a change in their attitude to work and a sense of wanting more out of life. Several participants also reported a change in the way they related to those around them, with an increased empathy towards the difficulties of others and a tendency not to focus on the 'less important things in life'. Similar results have previously been documented in the wider cancer literature where patients have reported on having made changes to their lives following their diagnosis (Hodgkinson et al., 2007), gaining appreciation for new areas (Westman et al., 2006) and generally seeing their cancer as a turning point (Pascal & Endacott, 2010). The present findings indicate that such experiences are likely to persist for many individuals after the completion of successful treatment, and lead to a new way of engaging with life and those around them.

### Freedom

Existential freedom is a deeply unsettling concept for many people, as it emphasises the fact that life is uncertain and all human beings are responsible for their own lives (Yalom, 1980). The theme of 'uncertainty' was ubiquitous across the dataset. Many participants talked about

the sense of uncertainty they experienced around the possibility of recurrence, but others also discussed the lack of certainty they had experienced once the structure accompanying treatment had been removed. Both forms of uncertainty had led to feelings of distress and anxiety for the participants and they had often sought ways of re-establishing this structure, either by information seeking or by trying to achieve a sense of normality. Uncertainty is a widely acknowledged concern in the cancer literature, but has previously mainly been examined in relation to fears around recurrence, which can exist for patients at any stage of the cancer journey (Halldorsdottir & Hamrin, 1996). This uncertainty is one of the most difficult aspects of living with cancer (Cohen, 2004; Ferrell, Grant, Funk, Otis-Green & Garcia, 1998), and can frequently lead to feelings of distress (Pascal & Endacott, 2010) and a need for structure and certainty (Halldorsdottir & Hamrin, 1996).

In the present study, the uncertainty expressed by participants not only related to the uncertainty of recurrence, but also touched on the more general sense of uncertainty experienced once treatment had ended and the structure of this had been removed. Research has suggested that patients frequently do not wish to take active responsibility over their treatment (Beaver et al., 1996; Davison, Degner & Morgan, 1995) and often experience a sense of abandonment once treatment is over (Macmillan Cancer Support, 2006). Although patients' need for support and guidance is undoubtedly linked to fears around cancer itself, it could also be questioned whether the end of treatment may give rise to reflections around responsibility. Arguably, the structure experienced during treatment may temporarily remove patients' sense of authorship and responsibility over their lives. Once treatment has ended, the sudden loss of structure that follows, together with patients' increased awareness around their mortality, may serve as a reminder of the fact that they are authors of their own futures, however long or short these may be.

Indeed, participants in the present study reported a newfound sense of authorship and responsibility after the completion of treatment, as well as an awareness of the different choices available to them. At times, this appears to have given rise to some distress but for

many it had also provoked a wish to make active changes in their lives, such as improving their health. Others had consciously chosen not to take action, with an awareness of the potential negative outcomes of these decisions. These findings are reminiscent of Sartre's (1963) notion that all human beings are responsible for both their actions and their decisions not to act.

The concepts of authorship and responsibility from an existential perspective have previously not been well researched in the cancer literature. Responsibility has mainly been examined in relation to patients' decision making around treatment (e.g., Davison et al., 1995), or feelings of guilt over the cancer (e.g., Chapple, Ziebland & McPherson, 2004) but little has so far been written about responsibility in relation to patients' sense of direction following treatment. The findings of the present study suggest that the end of treatment can serve as a catalyst through which patients are confronted with their existential freedom, something which can be both anxiety provoking and lead to a newfound sense of authorship in life.

### Isolation

Existential isolation can be defined as the experience of an unbridgeable gulf between the self and another (Yalom, 1980). The participants' sense of isolation in the current study was striking. They spoke about how cancer had brought on a sense of difference between themselves and others, which was particularly noticeable in the post-treatment phase. For many, this experience of difference seemed to be of an emotional nature but for some it also related to physical changes, which continued to remind them of their disease even after their treatment had ended. Contact with other cancer survivors or cancer services did not seem to fully alleviate these feelings of isolation, as participants remained aware that no one else could fully share or understand their particular experience in the way they did. These findings are congruent with Yalom's (1980) suggestion that awareness of one's mortality often emphasises to the individual that life is a unique and existentially lonely experience, which cannot be fully shared with anyone else.

These findings support and add to those of previous research, which has shown that isolation can be experienced at many different stages of the cancer journey (Arman, Rehnsfeldt, Lindholm & Hamrin, 2002), not least in the post-treatment phase (Halldorsdottir & Hamrin, 1996). One reason for this may be that cancer survivors often experience a sense of social stigma and can be seen as 'omens of hazard' and discouraged by society from expressing their feelings (McKenzie & Crouch, 2004). As such, the inherent existential isolation experienced by all human beings may be exacerbated by those in the post-treatment phase via a sense of 'otherness', of being an outsider, different.

Although the experience of existential isolation may be inevitable for many cancer survivors, the presence of social support seemed to alleviate some of the distress experienced by the participants in the present study. Many had sought out and benefited from increased closeness with their family, friends and church since ending treatment, and some discussed the difficulty in dealing with the reality of cancer without such support. The importance of social support has been emphasised in previous studies, where social stigma, unsupportive relationships and the lack of a significant other have been linked to poorer adjustment and low emotional well-being (Else-Quest, LoConte, Schiller & Hyde, 2009; Figueiredo, Fries & Ingram, 2004; Powe, 1996). Congruently with the present study, religion has also been found to play a fundamental role in provoking feelings of security for individuals living with cancer (Landmark et al., 2001).

According to Heidegger (1962), there are moments in all humans' lives when the reality of existential isolation becomes particularly apparent. (Fromm, 1956) added to this by suggesting that the development of strong social relationships may serve as a form of defence against such feelings of isolation. The findings of the present study seem to suggest that individuals in the period following treatment for cancer can often experience isolation of an existential nature, and that many respond to this by establishing and drawing on close relationships in life, whether with family, friends or religious affiliations. Although social support is undoubtedly very important, it does not seem to fully alleviate the feelings of



isolation, as a degree of separation will arguably always exist between all human beings. It appears that the confrontation with this reality is one of the biggest challenges for individuals in the post-treatment phase.

### Meaning

Meaning formed a core part of the narratives presented by the participants in the study. For some, the end of treatment was accompanied by a loss of meaning, whereas for others, it had led to a newfound sense of purpose in life. The development of a robust sense of meaning has long been identified as a key part of human development (Yalom, 1980) and a prerequisite for dealing with emotionally challenging experiences such as cancer (Park et al., 2008).

Some participants in the current study talked about a difficulty in establishing a purpose in life since their futures may be time-limited. Previous post-treatment cancer research has indicated that although it can initially be difficult to establish a sense of meaning when the future is uncertain (Hodgkinson et al., 2007), this can be overcome via the means of self-exploration and social support (Nelson, 1996). The participants of the present study varied in the social support available to them, which may have affected their ability to create a sense of meaning.

Many participants also struggled with the way in which cancer had affected important aspects of their identities. In a review of the existential challenges faced by individuals with cancer, Henoch & Danielson (2009) reported that patients often perceive a range of threats to their self-identity and may struggle to maintain this. Research involving individuals in the post-treatment phase has shown that adverse effects may be felt by those whose sense of identity may still carry a stigma of being a cancer patient (Crouch & McKenzie, 2000). In the present study, the loss of identity had, for some, been specifically linked to gender roles, whereas for others, it had related to a general sense of lacking ability. This appeared to have had a considerable impact on participants' confidence and sense of purpose and belonging.

Yalom (1980) and Erikson (1963) have both suggested that a coherent sense of identity is essential to the individual's overall sense of meaning. Although additional research is required to explore the links between meaning and identity in more detail, it could be argued that the ability of individuals in the post-treatment phase to obtain a sense of meaning can often be dependent on the extent to which their sense of identity has been challenged by the cancer.

While it is clear that individuals in the post-treatment phase can often struggle to ascertain a fulfilling sense of meaning, many of the participants in the present study had experienced a newfound sense of meaning and purpose after completing treatment. This ranged from more 'hedonistic' sources of meaning, such as personal enjoyment and pleasurable activities, to more altruistic means. According to Yalom (1980), meaning can be experienced in a variety of ways and while 'enjoying life to the full' can be a deeply meaningful experience for some, the most fulfilling sources of meaning tend to be found in experiences that also benefit others. Participants in the current study expressed altruistic fulfilment in two ways. The first was via 'dedication to a cause', which indirectly carried an element of altruism, and mostly tended to focus around their families. The second, and more direct form of altruism, was seen in participants' wishes to support others who may be facing similar difficulties, as well as those experiencing other challenges.

Previous research has suggested that meaning making can play an important role for cancer patients' emotional well-being (Ramfelt et al., 2002), adjustment process (Park et al., 2008) and coping (Mullen, Smith & Hill, 1993). However, it can often be a challenging task, which many individuals struggle with for several years after ending treatment and may need professional support with (Moadel et al., 1999). The results of the present study support and add to previous findings. They suggest that meaning making in the post-treatment phase can be a challenge that may depend on the extent to which patients are struggling with the uncertainty of their disease and whether their sense of identity has been affected by the

cancer. The results also suggest that meaning making can take many different forms, a finding that has previously not been discussed in the post-treatment cancer literature.

### **Limitations**

The findings of the present study provide some new understanding of the existential experiences of individuals who have completed cancer treatment with curative intent and are in complete remission. However, certain limitations should be taken into account when considering these findings. Firstly, it should be noted that the findings were obtained using qualitative research methods, and may therefore not be generalisable to all individuals who have completed cancer treatment with curative intent. Adding to this is the fact that all the participants were of white UK ethnic background and of a relatively narrow age range. It is therefore difficult to determine whether a more diverse participant sample would have expressed concerns of a similar nature or whether the findings are limited to those cultural and social groups represented in the participant sample. Further research is needed to examine this area further.

### **Conclusion**

The completion of cancer treatment with curative intent is often considered an important milestone. Although the existential concerns of survivors clearly share many similarities with those who are currently undertaking treatment, experiences specific to the post-treatment phase were also evident. For many this aspect of the cancer journey carries its own unique challenges which impact on the individual long after treatment has ended. The findings of this study offer a new level of understanding around the shared difficulties faced by these individuals. They suggest that the post-treatment phase may serve as a catalyst for the existential concerns said to challenge all human beings, namely death anxiety, isolation, freedom and meaninglessness. While the individual may become more aware of their mortality and authorship, and therefore experience a wish to live a more meaningful life, the

reality of this may prove more difficult. Many individuals may have experienced a loss of identity and/or values as part of their diagnosis and treatment, and others may feel very isolated in their experience, thereby struggling to create a sense of meaning. It is hoped that the findings of this study can provide healthcare professionals with a better understanding of the challenges faced by this particular patient group and assist in the emerging shift from the predominantly medically focused existing model of post-treatment cancer care to a more holistic approach.

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